



Palliative and End-of-Life Care Reflective Discussion Video Segments

Instructional Video Teaching Guide

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TABLE OF CONTENTS

HOW ARE THE MATERIALS DESIGNED AND ORGANIZED?	4
WORKING EFFECTIVELY WITH THE INSTRUCTIONAL VIDEO SEGMENTS.....	5
OTHER HELPFUL TIPS	7
SEGMENT - PDV001 - ORIENTING OURSELVES FOR PALLIATIVE & EoL CARE WORK	8
SEGMENT - PDV002 - DISCUSSING GOALS OF CARE (PATIENT INCAPACITATED).....	10
SEGMENT - PDV003 - ENGAGING END OF LIFE CARE CONVERSATIONS	13
SEGMENT - PDV004 - ENGAGING CULTURE IN ADVANCED ILLNESS	16
SEGMENT - PDV005 - RECOGNIZING AND HAVING DIFFICULT CONVERSATIONS	19
SEGMENT - PDV006 - DISCUSSING GOALS OF CARE (DIVERGENT FAMILY VIEWS).....	22
SEGMENT - PDV007 - DISCUSSING GOALS OF CARE (ENGAGING TRANSITIONS).....	26
SEGMENT - PDV008 - DISCUSSING GOALS OF CARE (HASTEN DEATH REQUEST).....	29
SEGMENT - PDV009 - DISCUSSING AND DEMYSTIFYING THE LAST HOURS.....	32
SEGMENT - PDV010 - COLLABORATIVE TEAM WORK IN ADVANCED ILLNESS.....	35
PRODUCTION CREDITS	37

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The original production of the Materials was part of the *Pallium Integrated Care Capacity Building Initiative*, with a financial contribution from the *Government of Canada, Primary Health Care Transition Fund (PHCTF)*.

NOTICE OF ACCESS TO THE COMPANION VIDEO SEGMENTS

Companion video segments have been made accessible for download in a high-resolution Windows Media Video (.wmv) format and a MP4 (.mp4) format suitable for use on Apple Computer Inc (i.e., iPad, iPhone, iPod, QuickTime viewer) devices, Android OS devices, other devices capable of playing MP4 files, as well as Learning Management Systems.

ERRATA & SUGGESTIONS FOR IMPROVEMENT/FUTURE VERSIONS

The Canadian Pallium Project practices a process of continuous evaluation and improvement of educational products. Considerable efforts have been taken to assure the accuracy of the Materials, however, if you find an error or would like to share insights gathered in the course of using these materials for future versions please communicate by fax to 780 413-8196 or by mail to Pallium Transition Office, Box 60639, U Alberta RPO, Edmonton, Alberta, Canada, T6H-0W9.

HOW ARE THE MATERIALS DESIGNED AND ORGANIZED?

There are the ten instructional video segments covered by this kit:

- The segments present clinical scenarios associated with advanced-illness and dying. A cross-section of scenarios frame issues that may be experienced in a home, hospital, hospice, long-term/continuing care or settings of marginalization (e.g., street, remote/isolated small community). The segments may also be useful to prompt critical reflection and discussion about broader patient/family and provider relationship issues, including negotiating goals of care and the benefits of advance care planning (ACP). The principal thematic focus of the segments is on building and keeping constructive relationships with patients and families amid a variety of very challenging and difficult communication scenarios.
- The videos have been designed to discourage 'cookie cutter'/'recipe' use (i.e., blind modeling). They use an approach called 'ill-structured, sociodrama.' What is this?
 - Problems in professional practice are often ill-structured. That is, problems which possess multiple solutions, solution paths, fewer parameters which are less manipulable and contain uncertainty about which concepts, rules and principles are necessary for the best solution or how they are organized and which solution is best¹. Dr. Donald Schön² has described this as 'the problems of real-world practice do not present themselves to practitioners as well-formed structures. Indeed, they do not tend to present themselves as problems at all but as messy, indeterminate situations' (p. 4).
 - Sociodrama³ is a form of socio-therapy transcending individual personalities to present human social behaviour in general and focus on the 'group-as-a-whole.' Within these segments common clinical communication challenges/situations in Hospice Palliative Care have been identified.
- Sociodrama helps to simulate what happens in life to explore social issues, develop greater understanding between groups of people, problem solve and make decisions; observe roles and strategies and predict outcomes. Sociodrama is oriented to the wider social, political and cultural influences operating in any particular situation. It provides an opportunity for learners to explore situations from a variety of ill-structured (e.g., 'messy') viewpoints, to explore these through reflection and discussion, to gain a better understanding of why decisions are taken in a 'safe' educational environment and to consider what options might be available in practice.
- Each segment is designed with a voice-over narrative 'set up' and screen text to situate a context for the socio-drama. Four reflective questions are used to help frame critically-reflective discussions. Following the 'set up' is a dramatic enactment. At the end of the scenario there is the opportunity to use the PAUSE key to stop and debrief. Several segments have a second scenario which enables people to discuss variations in practice. Again there is an opportunity to PAUSE and debrief at the end of the second scenario. Each segment has a set of optional *Teaching Point Review* to support consistent debriefing/summation of the sociodrama segment.

¹ For further readings on this the facilitator is directed to Jonassen, D.H. (1997). Instructional design models for well-structured and ill-structured problem-solving learning outcomes. *Educational Technology: Research and Development*, 45(1), 63-85 and Murphy, E. (2004). Identifying and measuring ill-structured problem formulation and resolution in online asynchronous discussions. *Canadian Journal of Learning and Technology*, 30(1).

² See Schön, D. (1987). *Educating the reflective practitioner*. San Francisco: Jossey-Bass.

³ Perhaps one of the best current discussions of sociodrama can be found in Kellerman, P.F. (1998). Sociodrama. *Group Dynamics*, 31, 179-195.

WORKING EFFECTIVELY WITH THE INSTRUCTIONAL VIDEO SEGMENTS

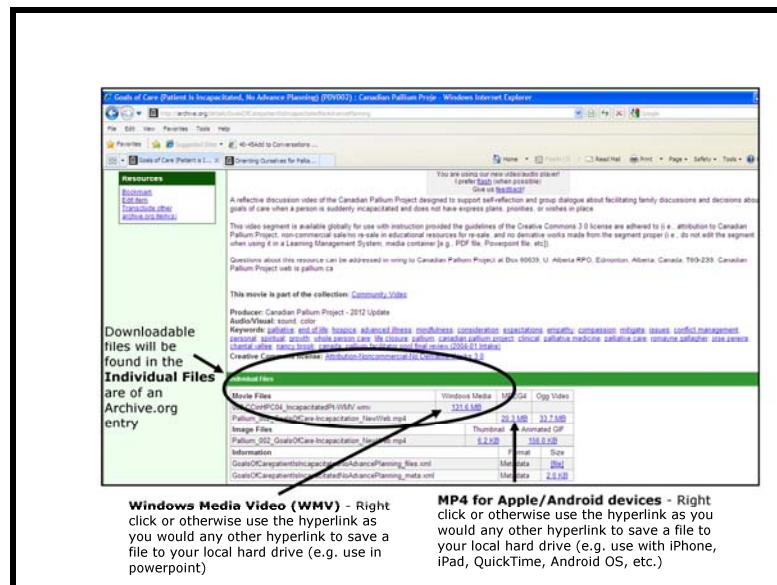
In order to most effectively use these materials consider the following:

Pre-instruction Preparation

- Access the web and source the individual archive.org entry of the video segments you wish to use. Enduring web locations for each segment are published in the guide.



- Download the video files that you require from the bottom of the archive.org entry. Alternatively, and provided you are confident about the reliability of the web access during the instructional event, you may also stream the Flash version of the video directly from the archive.org entry.



- Review the segments for applicability to the particular learning objectives of your session. The segments are designed to be incorporated within a range of clinical education and continuing professional/staff development applications.
- Take notes of the issues, the dynamics among characters in the scenarios of the segments. Draw on clinical experience and as well as strategies considered as ideal for a particular circumstance and model and exemplary practices of colleagues and be prepared to discuss these in contrast and comparison to that which is presented in the scenarios. Note the obvious as well as the subtle communication deficiencies and strengths that have been incorporated with various approaches as a means of promoting critical dialogue among participants regarding communication practices. A worksheet is included in the appendix to assist you in organizing your ideas/notes.

During Instruction

- Introduce the idea of 'sociodrama' as a teaching tool using the description of design concepts outlined on the previous page.
- Brief participants that the segments are, by design, NOT intended as conceptions of best practice. They are intended to be reasonably ill-structured and dramatic to generate dialogue, critical reflection, to reinforce the complexity of professional practice and the ambiguity of working within what are often very challenging and difficult value and ethical conflict-laden environments requiring professionals to communicate effectively and with empathy, compassion and understanding.
- Explain to participants that given the difficulty that many people currently have in engaging issues associated with care of the dying in our culture, a tone of melodrama has been purposefully introduced into several segments to 'lighten' the tone of the topics and issues for the purposes of facilitating learning. In test use of these segments this has proven an effective means of supporting a 'safe' learning environment and facilitated engagement and discussion by learners.
- Give participants an overview of what they will see and why it is being presented.
- Instruct the group on what to do during the viewing. It is useful to write out the four item reflective question set on a white board, flip chart or distribute as a handout.
- Debrief after each scenario is used and summarize key points you want retained.

OTHER HELPFUL TIPS

- Each segment has a note on the first slide indicating there is a clinical disclaimer at the End of Segment. Every viewer ought to be informed that use of the video is subject to the clinical disclaimer.
- If you use these segments solely to discuss communication issues, then an alternative approach to the reflective question set included in the segments is to pose the following questions to guide participant group learning exercises:
 1. Identify what you (participants) feeling is done well by the health professionals.
 2. Identify how they (participants) would improve the communication if they were in the same situation as what they are witnessing in the sociodrama scenario.
 3. Think of useful approaches, quotes and phrases that they (participants) would use in the same situation.
- Consider using Robert Buckman's* Six Step Protocol for discussing difficult news:
 1. Get the physical context right
 2. Find out how much the patient knows
 3. Find out how much the patient wants to know
 4. Share the information
 5. Respond to the patient's feelings
 6. Make a plan and follow through

* See Buckman, R (1998). Communication in palliative care: A practical guide. In D. Doyle, GWC Hanks & N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (2nd ed., pp. 141-156). Oxford: Oxford University Press

- Predictable and challenging questions encountered in end-stage care include:

Questions or statements such as

- How long do I have to live?
- Don't tell him/her he is dying (or has cancer)! It will kill him!
- I found this on the internet – it's a cure for cancer
- What is the end going to be like?
- What do I say to my dying mother?
- The doctors should have found this earlier. If they had treated it earlier, she would have been cured.
- Do not hydrate him. You are simply prolonging his suffering.
- Surely you will feed her?

Situations including

- Requests to continue aggressive/curative treatment for disease even when it is showing no benefit and perhaps even causing more harm.
 - Discord amongst family members where a patient is non-communicative and sufficient advanced care planning has not taken place.
 - Denial about a life-threatening circumstance being life-limiting
- Users having access to *Learning Essential Approaches to Palliative & End-of-Life Care* (LEAP) Facilitator Kits may find additional useful instructional information in Module 5 (Communication) to support their instructional objectives in use of this material.

SEGMENT (PDV001)
ORIENTING OURSELVES FOR PALLIATIVE AND END-OF-LIFE CARE WORK
Running Time (without participant discussion) – 4 min, 42 sec

Access at
<http://archive.org/details/OrientingOurselvesForPalliativeAndEnd-of-lifeCareWorkpdv001>

Suggested Use - Reflecting on our own state of being in relation to patient/family

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents a reflective scenario. It's not intended to model but rather to promote critical reflection and group discussion about the importance of being centred in our work.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO

NURSE (Monologue to audience and into scenario)

When I was first starting out in nursing I used to barge into a hospital room without really thinking about what was going on behind the door.

But... thankfully, there was one family... one person ... that actually made a difference for me.

It happened one night... when I was on a busy evening shift.

I was behind in my rounds, so naturally...I was in a hurry.

Later that evening, when things had slowed down, a patient's daughter , asked me if we could talk.

I had a few minutes, so I said yes.

That's when she told me she'd been taught that a person nearing the end of life needs to be in a space that is kept sacred. Held sacred so that the ancestors will feel comfortable to come and help with the journey, the journey their loved one will make to the other side.

Without quiet and stillness, her mother might not feel the presence of the ancestors... and might wonder if she's been deserted.

She asked me if I could carry out my duties more quietly and gently.

Actually I remember exactly what she said...

... "make a smaller ripple in the energy of the room"....

Now, no matter how busy I am, I always ... stop... look... and listen.

I stop... or just slow down a little before I enter a patient's room.

As I enter the room, I take a moment to look at what is going on. I take the time to connect with the family and patient's experience... coming from a place of compassion... I do the best I can in the moment.

Then I listen. I listen to what is going on in the moment. I listen to my own emotional state... am I rushed?... stressed?... am I tired?... and finally... I check my mind...what am I telling myself... what am I thinking... then I calm myself and stay as quiet as I can inside.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario screen up
Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

As the scenario illustrates, it really doesn't take much more time to briefly stop and reflect on where we are at in the moment when engaging patients and families experiencing life-threatening and life-limiting illness.

We are constantly challenged to balance the physical, psychological, social, spiritual and practical needs of our patients and their associated expectations, needs, hopes and fears.

Being constantly mindful and considerate of a range of expectations, traditions and a patient and family's specific experience with an illness can have a significant influence on preventing new issues from occurring.

It can also contribute to a care setting that promotes personal and spiritual growth, as well as important life closure tasks.

END OF SEGMENT

SEGMENT (PDV002)
GOALS OF CARE (PATIENT IS INCAPACITATED)

Running Time (without discussion) – 7 min, 52 sec

Access at

<http://archive.org/details/GoalsOfCarepatientIsIncapacitatedNoAdvancePlanning>

Suggested Uses

- Communication challenges in situations where goals of care and intentions have not been anticipated or articulated prior to a patient's incapacitation
- Predictable communication challenges in the absence of advance planning
- Facilitating communication and goals of care in cases of patient incapacitation

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents two ill-structured scenarios. It's not intended to model but rather to promote critical reflection and group discussion on the challenges of working with families to make decisions following an unexpected, life-threatening illness.

In this scene, a stroke robs a patient of decision-making capacity and leaves the family with difficult choices to make. Using a family meeting, providers discuss prognosis and explore future treatment.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO ONE

HUSBAND

Rose, everyone's here to see you today, hun.

DAUGHTER

The Reverend has you on the prayer line... so there's lots of people prayin' for you.

HUSBAND

You have old Ethel Pruett sending off prayers for you. And you know how strong she prays.

DAUGHTER

And JoJo, just won the intramurals... Tell mom, JoJo.

SON (JoJo)

I feel so stupid doing this. She can't hear us. She doesn't even know we're here.

HUSBAND

We don't know that ...

NURSE

Excuse me folks, Dr. Beckett is ready to see you in the family room now. I'll just wait outside until you're ready to go.

PHYSICIAN (Dr. Beckett)

Well, that's where we are with Rose's treatment. Basically, we've had no response from her in the last week. Her periods of consciousness are not lucid. She doesn't understand anything, she doesn't appear to recognize anyone.

Her recent C.A.T. scan indicates the intracranial bleed has been extensive, and large portions of her brain have been damaged. In the end, her condition has not improved, it's deteriorated.

NURSE

All the nurses who are caring for her, say she hasn't responded to any outside stimulus lately.

HUSBAND

But she blinked, when I spoke to her yesterday. I think she's doing better.

PHYSICIAN

That could have been just a reflex. Not an acknowledgement of your presence, Mr. Baines. You know, for all intents and purposes, Rose is not getting better. I believe that we should stop the treatment.

DAUGHTER

And what does that mean?

PHYSICIAN

We'd like to remove the feeding tube.

SON (JoJo)

So, she'll just starve to death? You can't just pull the plug on her. That's my mom.

PHYSICIAN

In her condition, she is dying anyway. At this point we are merely prolonging the inevitable.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario One screen up
Pause for Discussion

Press **PAUSE** key and debrief

RUN SECOND SCENARIO

Press **PLAY** key / **PAUSE** key

SOCIODRAMA SCENARIO TWO

PHYSICIAN

As you know, your mother has had a severe bleed into the brain. When we started treatment we high hopes that she could recover. But so far, to this point, we've not seen any response to stimulus.

NURSE

And the nursing staff reports that her periods of consciousness... times when her eyes are open, are becoming shorter and far less frequent.

PHYSICIAN

Dennis, are you noticing anything?

HUSBAND

I thought I saw her blink at me the other day when I was speaking to her.

PHYSICIAN

Well, now, do you think that she recognized you, or do you think it's just a reflex?

HUSBAND

... ah... well... I always talk to her, you know... Never used to be able to get a word in. No... no... I don't think she's doing any better.

DAUGHTER

It's only been a month. That's not very long. I've heard of people waking up after being in a coma for years. Mom could still wake up.

PHYSICIAN

Perhaps if she were young, and the brain had not been too severely damaged, then she might recover. Some people do that. But your mom has had very extensive damage to the brain. Have you seen any indications that she has improved?

DAUGHTER

No ... not really. When the nurses turn her she doesn't open her eyes like she used to.

PHYSICIAN Joseph, what about you?

SON (JoJo) It's JoJo and I think mom's already gone.

PHYSICIAN

So, what do you think your mom would want now?

SON (JoJo)

I don't think she'd want to be hooked up to all those machines...She was a proud woman. She wouldn't want to be so helpless. There's no dignity. I hate seeing her like this. I think she'd want us to pull the plug.

REVEREND

JoJo is right about his mother. I remember in a conversation I had with her not long ago, she said that when the Good Lord called her home she hoped it would be quick.

PHYSICIAN

Dennis, you don't agree?

HUSBAND

It's not that I don't agree. In fact we promised each other the same thing, no being hooked up to machines... dying with dignity and all... but... that was when we were healthy. This happened so fast... what if she changed her mind? I mean you said people have recovered from comas.

PHYSICIAN

Listen, you do not have to make any decisions right now. In the meantime you and your family go home, talk about how your mother's treatment is proceeding and how you see it going on from here? And whatever your decision, we will make sure that Rose is kept as comfortable as possible.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario Two screen up

Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

The segment highlights the ways in which care providers can help facilitate goals of care discussions with family members.

A key question like 'what would she have wanted?' can be helpful to allow families to speak and tell stories. It's the shared exploration of these stories that gives insight into a patient's possible wishes about goals of care.

Giving the family a chance to express their concerns and hearing their assessment of the patient's situation engages the family in the decision-making process.

It's important to be thoughtful and careful to use language that the family understands.

Decision-making is a process, not a moment. In situations such as these it sometimes takes a series of meetings, giving the family time to reflect, discuss and adjust to the changing situation of their loved one.

END OF SEGMENT

SEGMENT (PDV003)
ENGAGING END OF LIFE CARE CONVERSATIONS
Running Time (without participant discussion) – 5 min, 41 sec

Access at
<http://archive.org/details/EngagingEnd-of-lifeConversationspdv003>

Suggested Uses

- Recognizing patients seeking to engage end-of-life conversations for progressive chronic illness
- The importance of creating “safe” spaces for patients and families to commence end-of-life planning/life closure work
- Provider/patient leadership and accountability for engaging end-of-life care planning conversations
- Progressive heart disease-related end-of-life care conversations

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents two ill-structured scenarios. It's not intended to model but rather to promote critical reflection and group discussion. Our patients can be down-to-earth people seeking leadership from their clinicians.

George has a history of progressive heart disease that has advanced, is concerned about what the future holds, and he and his wife turn to his physician for guidance and answers.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO ONE

GEORGE (HUSBAND)

Well, the old heart was beating this morning... is it still working?

FAMILY PHYSICIAN

It's still working George.

GEORGE (HUSBAND)

Good, I am a little short of breath though... not doing too badly. Sure was glad to get out of that hospital... thought they'd never let me go home!

FAMILY PHYSICIAN

I bet you were. Let's just check your blood pressure.

Looks like you're both doing a pretty good job... George, you're blood pressure is in good shape today. Keep checking your weight, and taking your medications every day. Call me if your weight goes up and I'll increase your water pill. I want to see you in two weeks.

HADDI (WIFE)

Do you really think he's doing okay?

FAMILY PHYSICIAN

You're both doing a great job Haddi. We'll see you.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario One screen up
Pause for Discussion

Press **PAUSE** key and debrief

RUN SECOND SCENARIO

Press **PLAY** key / **PAUSE** key

SOCIODRAMA SCENARIO TWO

GEORGE (HUSBAND)

Well, it was beating this morning... is it working..?

PHYSICIAN It's still working George.

GEORGE (HUSBAND)

Good, a little short of breath though.

PHYSICIAN Are you?

GEORGE (HUSBAND)

Not doing too badly. Sure was glad to get out of that hospital... thought they'd never let me go home!

PHYSICIAN

What was the hardest thing about being in the hospital?

GEORGE (HUSBAND)

Everything, the noise, the tests, and the food... it was awful! Those hospital beds are like slabs of stone! The good Lord knows I'm going to be sleepin' on one of them soon enough.

HADDI (WIFE)

Oh, George you've got lots of good years left in ya!

GEORGE (HUSBAND)

But I can tell time's gettin' short.

HADDI (WIFE)

Now George, I don't want you talking like that.

PHYSICIAN

Well, Haddi, you both know that George's heart condition is getting worse. And George your comfort and quality of life are the most important things for us to consider. We've talked before about how unpredictable heart disease can be... and George your heart is getting weaker.

GEORGE (HUSBAND)

How much time are we lookin' at, Doc.

PHYSICIAN

It's hard to say. You're not a statistic George. But I'd say we're lookin' at months rather than years. Have you talked about the future?

HADDI (WIFE)

Yes we have. I'd like to take care of him at home.

PHYSICIAN

Maybe we should set up another appointment for you to come in and talk about your options for care. Things like where and what you'd like that care to be.

GEORGE (HUSBAND)

That would be much appreciated Doc.

PHYSICIAN

Okay then, let's just take a look at your blood pressure.

PARTICIPANT DISCUSSION & DEBRIEF

**End of Scenario Two screen up
Pause for Discussion**

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

With careful listening to the patient and family, there are 'cues' that the health care provider can pick up on. These are 'openers' for important discussions about advanced planning.

Many patients are reluctant to bring up the topic of end-of-life care, but may welcome the opportunity to discuss it when a provider introduces the topic.

The provider can learn to ask 'skilful questions' that help identify the inner feelings and deeper meanings of what the patient or family is saying. This approach can be helpful in introducing end of life issues.

With regards to prognosis, we need to be careful and ask ourselves the question – do we need to give patients the 'answers' all the time? We need to ask ourselves, why are we giving an answer in this instance?

We also need to be careful that as health care providers, we're not getting caught up in a curative mode and losing sight of patient and family concerns.

END OF SEGMENT

SEGMENT (PDV004)
ENGAGING CULTURE IN ADVANCED ILLNESS
Running Time (without participant discussion) – 5 min, 34 sec

Access at
<http://archive.org/details/EngagingCultureInAdvancedIllnesspdv004>

Suggested Use

- Communication issues in effectively engaging and managing diversity of values, practices and cultural protocols in contemporary clinical culture

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents two ill-structured clinical scenarios. It's not intended to model but rather to promote critical reflection and group discussion on the reality that we are faced with when family expectations conflict with our sense of professional duty and ethical responsibility.

How we engage and integrate a diversity of cultures and expectations can be central to how a patient and family understands and responds.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO ONE

ELDEST SON OF PATIENT (JOE) Dr. Johnston?

PHYSICIAN (DR. JOHNSTON) Yes...

JOE I'm Joe Singh, Mrs. Singh's son. You're seeing my mother today right?

DR. JOHNSTON Yes I am.

JOE I wonder if I might speak with you for a moment about my mother?

DR. JOHNSTON Of course! What is it you'd like to talk about?

JOE It's about the cancer. She knows she's sick but she doesn't know how sick she is. We'd like to keep it that way.

DR. JOHNSTON

I'm sorry, Mr. Singh, but I don't work that way. She has a right to know about her cancer and her condition. I have to tell her about her treatments and what we can do for her.

JOE But Physician, that's not how we do it in our culture.

DR. JOHNSTON

I understand, but I have to talk with her. I have about ten minutes before my next appointment, so let's talk with her now.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario One screen up
Pause for Discussion

Press **PAUSE** key and debrief

RUN SECOND SCENARIO

Press **PLAY** key / **PAUSE** key

SOCIODRAMA SCENARIO TWO

ELDEST SON OF PATIENT (JOE) Dr. Johnston?

PHYSICIAN (DR. JOHNSTON) Yes...

JOE I'm Joe Singh, Mrs. Singh's son.

DR. JOHNSTON Oh, pleased to meet you.

JOE I was wondering if I might speak with you for a moment

DR. JOHNSTON Of course! Would you like to talk in private?

JOE If we could, yes.

DR. JOHNSTON Okay, there's a room down the hall where we can go. Follow me.

DR. JOHNSTON Now Joe, what would you like to talk about?

JOE Mother knows she's ill... but she just doesn't know or understand how ill she really is.

DR. JOHNSTON But she's been told the tumor was cancer?

JOE

Mother doesn't understand English very well, and ... when the surgeon told her about the illness... we translated for him, we left out the part about it being cancer... we told her it was a tumor that the surgeon removed and now we're afraid she'll figure it out... with the Physicians, like yourself, talking to her.

DR. JOHNSTON

I don't understand. It's my belief that it's important for her to know about her illness... that there are treatments available. And some of those treatments could make her relatively uncomfortable.

JOE

Yes, I know. And this may not be easy for you to understand but in our culture it is preferred that the patient not be told. It is the duty and responsibility of the family to look after the patient. We are to see that her journey is as easy as possible... it's a matter of respect... and honor.

DR. JOHNSTON And you feel that this is what your mother wants?

JOE

Yes. This is what she when her husband when he was sick with heart failure. It is a long respected tradition, and mother... is very traditional.

DR. JOHNSTON

But Joe, I still have to arrange treatment for your mother. How can I do that without telling her what's going on?

DR. JOHNSTON

How about trying this with me? We'll both go to see her and I'll ask her if she prefer that the family be told the details of her illness and if she'd like them to make decisions for her. And if she agrees then that's how we'll proceed.

DR. JOHNSTON

But Joe, you must understand if she asks me any questions about her diagnosis or prognosis... I'm obliged to answer them.

JOE Of course you must answer... that is also respectful.

DR. JOHNSTON Ok, shall we go talk with your mother now.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario Two screen up
Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

As the second scenario illustrates, being receptive to family concerns and exploring underlying interests, such as the hopes, fears, needs, desires, and concerns of patients and families as well as important values is one way to more effectively engage a family.

It is possible to remain true to our ethical principles and duties as clinicians, while honouring different traditions.

Cultural competence is obviously more than attending to matters of disclosure and autonomy, but we can demonstrate our openness and willingness to engage families with these issues.

Respecting different traditions and adapting our communication to those principles is likely to result in a better outcome for the patient and family. It contributes to creating an environment of comfort, dignity and peace-of-mind.

END OF SEGMENT

SEGMENT (PDV005)
RECOGNIZING AND HAVING DIFFICULT CONVERSATIONS

Running Time (without participant discussion) – 6 min, 33 sec

Access at

<http://archive.org/details/RecognizingAndHavingDifficultConversationspdv005>

Suggested Uses

- Exploring the importance of primary-care professionals communicating with specialist and other colleagues about life-changing information
- Reflecting on the importance of framing clinical information sharing in ways patients can readily engage and around which understanding can be built

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents two ill-structured scenarios. It's not intended to model but rather to promote critical reflection and group discussion on the challenges associated with discussing bad news.

In this scene, a family physician is visiting his patient after he has had surgery for a colon cancer. The surgeon also found metastases on the fatty tissue around the bowel and the lining of the abdominal cavity.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO ONE

PHYSICIAN RUPERT (Monologue to audience)

I'm about to visit John Philpot. He's recovering from surgery. He had a bowel tumor removed and evidence of metastases. This means that John's cancer is incurable. Now I know the surgeon has talked with John, but I don't know if John really understands his condition.

JOHN (Monologue to audience)

I'm feelin' pretty good. Yeah, I've got some pain, but the surgeon got my tumor. It was attached to my bowel. But the most important thing is that the tumor is gone! Probably be out of here in a few days once they can remove these tubes and get me on some decent food. I'm sure everything's gonna be okay. No biggy, as my son says.

PHYSICIAN Hi John

JOHN

Hello, Dr. Rupert.

PHYSICIAN

I was sorry to hear the news... we were hoping that surgery and a course of chemotherapy would cure this tumor.

JOHN

What do you mean?

PHYSICIAN

When a tumor spreads through the abdomen like yours has, there's a limited amount that we can do for you.

JOHN

What do you mean, spreads through the abdomen like mine has? The surgeon said he'd removed the tumor...

PHYSICIAN

Yes, the primary one, but he couldn't get all of the places it had invaded. We need to give you chemo for that...

JOHN

What do you mean invaded?... you keep talking about this chemo stuff...

PHYSICIAN

Didn't the surgeon talk with you?

JOHN

Yeah, but he didn't say anything about chemo or invasive stuff... what the hell is going on here? I thought I was cured... Now it sounds like I'm not.

PHYSICIAN

I'm sorry John, I thought you knew...

JOHN

Well I didn't. I don't believe it. They've shown you the wrong chart. I'm going to be fine. Just need a little medicine and I'll be right as rain.

PHYSICIAN

Okay John...I'll be back later

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario One screen up
Pause for Discussion

Press **PAUSE** key and debrief

SECOND SCENARIO

Press **PLAY** key / **PAUSE** key

SOCIODRAMA SCENARIO TWO

PHYSICIAN Hello John

JOHN Hello, Dr. Rupert.

PHYSICIAN So, how are you feeling today?

JOHN

I hurt some, but I guess that's what you get when you let someone go poking around in your belly. But I gotta say the nurses have been great.

PHYSICIAN Do you have enough medicine to control the pain?

JOHN Oh no, I'm just fine. Mostly, I just want to get these tubes out of me and go home.

PHYSICIAN The Surgeon has talked with you?

JOHN Yeap... and another Physician, an onokello-callo... something or other.

PHYSICIAN Oncologist?

JOHN Yep, that's it.

PHYSICIAN

Do you want to tell me what you understand about your illness to this point?... Just so I know we're both on the same page.

JOHN

Yeah, sure. They said that they had removed a tumor from my bowel and that I might need some chemotherapy. That drug stuff worries me a little though.

PHYSICIAN Do you know why you need the chemo?

JOHN Yeah, something about cleaning up the cancer after surgery.

PHYSICIAN And what do you understand about the future?

JOHN

Even though I'm scared of the chemotherapy drugs, I'm sure that they'll cure me. No worries.

PHYSICIAN Did the surgeon tell you about what he found?

JOHN Yeah, some invasion of the fatty tissues and covering of the bowel.

PHYSICIAN And what did he tell you about that invasion?

JOHN Well, he said that it wasn't good news.

PHYSICIAN John, how are you feeling about all of this?

JOHN Scared.

PHYSICIAN Anything I can explain to you?

JOHN Actually, the oncologist has told me everything I want to know at the moment.

PHYSICIAN

John, we are all here for you, and if you need to talk to me or anyone, just let the nurses know.

JOHN Thanks Dr. Rupert. Glad you could drop by.

PHYSICIAN I'll see you again in a couple of days, ok?

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario Two screen up
Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

This scenario illustrates that a family physician, nurse or other member of the care team is often involved with a patient after they have had information from other providers.

Presuming a patient has the same understanding of the illness as the care provider can be very destructive.

Asking a patient for their understanding of the illness is key to communicating about bad news and helps guide the necessary conversations. It can be helpful to literally and physically sit down with a patient to discuss concerns of this nature.

Asking about patient's feelings and underlying interests can make them feel supported and cared for. It encourages them to express feelings in the future because the care provider has considered them important enough to ask about.

END OF SEGMENT

SEGMENT (PDV006)
DISCUSSING GOALS OF CARE (DIVERGENT FAMILY VIEWS)

Running Time (without participant discussion) – 12 min, 42 sec

Access at

<http://archive.org/details/DiscussingGoalsOfCaredivergentFamilyViewsdpdv006>

Suggested Uses

- Issues in navigating care when there is divergence within the family unit
- Issues with complications associated with possible existential suffering
- Exploring the importance of dynamics operating at family meetings
- Exploring the importance of mental health considerations in assessment

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents an ill-structured scenario. It's not intended to model but rather to promote critical reflection and group discussion about engaging families to find common ground and understanding, especially when conflicting views exist about what is right or what should be done.

In this scenario, a mother with advanced cancer and her three children hold significantly varying views about the situation and what should be done.

A family meeting is used as a backdrop to illustrate issues and roles for providers in situations with challenging family dynamics.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO

NURSE Are you comfortable Mrs. Allen? Any pain?

MRS. ALLEN No pain, just tired and sleepy. I think I'll take a nap soon.

NURSE Sounds like a good idea. If you need anything just ring.

PATIENT (MRS. ALLEN) (Monologue to audience)

Yeah, I'm sluggish. I sleep a lot, but I'm not that uncomfortable.

It's just too bad that my children don't understand. Oh, I know they're worried but I just don't want to prolong this... I don't want to suffer. I wish I could make them understand that the treatment isn't going to make what's left of my life any better. And I won't necessarily live longer or better with a lot of treatments. In fact, I'm afraid... that I might suffer more. I think it's time to just let nature takes its course.

SON (JAY) (Monologue of son to audience)

Mom just wants to be left in peace. She's been through a lot. She just wants some dignity and rest. All this fighting between my oldest sister Sandra and her about having treatments and not having treatments, just upsets her... a lot.

I don't understand, why she can't just let Mom make the decision. It's Mom's choice not Sandra's. Poor Cathy. The more Mom and Sandra argue... the more depressed Cathy gets.

YOUNGER DAUGHTER (CATHY) (Monologue of daughter to audience)

I don't know what to do. I don't know what to say... I don't know what's right... or wrong anymore... I just... I don't... ahhhh... to hell with it!

OLDEST DAUGHTER (SANDRA) (Monologue of oldest daughter to audience)

This is all Dad's fault that Mom is sick and depressed. I think she should get the treatment and get better. Jay thinks she should do whatever she wants...what kind of support is that. I think he gets this attitude from dad's side of the family. And Cathy, well she's just too (explicative!) quiet to say anything. I guess it's just me left to fight for mom... I only wish she'd listen.

DR. BARLOW I'm glad that all of you could make it today.

SANDRA

I don't see why we're here... It's pretty clear Mom needs treatment and she's refusing it. I don't know why we have to meet. You're her Physician... you talk to her... tell her what's right.

JAY Sandra, there is no "right" here. It's what Mom wants. Just relax will you!

DR. BARLOW We're here to talk...

SANDRA Yeah, talk...

MRS. ALLEN

Sandra please, this is important... Please for me... this is my life... I've spent my whole life doing for you kids. I think it's about time that you all let me do something for me... just for a change.

SANDRA Don't start with that guilt stuff again, Mom. I mean really....

DR. BARLOW

Okay... I think we need some rules so that everyone gets to say what they need to say without being interrupted. And that we listen to each other. Good, we'll start with Mrs. Allen, then Nurse Wesley, then Cathy, Sandra, and Jay.

MRS. ALLEN

Look kids... I'm dying...and nothing, short of a miracle, is going to change that...

SANDRA So what's wrong with hoping for a miracle...

MRS. ALLEN

I want a miracle more than any of you can imagine. But I'm tired. I'm tired of being sick. I'm tired of having pain. I'm tired of all the tests... I'm tired of needles... I'm tired of hoping. I'm tired of fighting with you Sandra about what is best for me. I just want to have as little pain as possible for my last weeks and days here.

CATHY So you're just gonna starve yourself to death then?

DR. BARLOW Mrs. Allen, are you hungry?

MRS. ALLEN

No. It's just like you told me. The cancer is producing a chemical that's taken away my appetite.

DR. BARLOW

And so you don't want to eat... but as of this morning, you asked us to remove your I.V. as well?

MRS. ALLEN That's correct.

DR. BARLOW Is there anything you'd like to add?

MRS. ALLEN No.

DR. BARLOW Okay... Nurse Wesley, would you like to say something?

NURSE

I would just like to say that Mrs. Allen and I have had many discussions about how she feels. And I've asked her if it was okay if I said what I'm about to say. She's given me her permission. She has indicated -- several times -- that the biggest pain she has is watching her family fight and argue over her choice for palliative care only. She says that the physical pain is no match for the emotional pain

she has when she sees all of you fighting. She just wants you all to understand where she's coming from.

DR. BARLOW

Thank you, Wesley. Cathy is there anything you'd like to say?

CATHY No.

DR. BARLOW Are you sure?

CATHY

What's to say... Mom's dying and she's willing to die... nothing I can say will change that.

MRS. ALLEN

Cath! I'm not willing to die but there isn't any choice and I've made my peace with that.

CATHY

Whatever... I don't know what else to think... I'm tired too, Mom. I'm tired of seeing you in pain... I don't know what's right anymore.

SANDRA I think it's my turn, and I've had plenty to say.

JAY What's new about that...

SANDRA

I don't think that Mom's made peace with dying so much as she's depressed. Come on think about it. Daddy was always drunk and Mom blamed herself thinking he was drinking because of her. Then he runs off with a woman half her age. And once again she thinks she let him down. Then he divorces her... and to round off everything... you guys diagnose her with pancreas cancer. Mom's not having a bad day... she's having a bad life. Don't you get it... she's giving up because she's depressed. And you guys are letting her. There's got to be something that you can do for her. You can't let her give up like this. You can't give up now.

Mom, for the first time you're free from Dad and all that trouble. This was supposed to be the time... to enjoy life... you can't give up now... please... you have to fight this.

Mom you've been unhappy for so long... I just want to see you have some good times...

JAY

I think I can understand where Mom's coming from in a way. Being tired and all. Just can't imagine what it's like for her. I can understand where Sandra is coming from too. Even though she can be a real pain in the... "all together"... But I still think that Mom's decision for treatment and how she lives her life is her choice. It doesn't matter what I want.

DR. BARLOW And what do you want, Jay?

JAY

I want a miracle I guess! I hate thinking about Mom suffering or dying. It haunts me everyday. But most of all I want what is best for Mom.

NURSE

I've seen all of you visiting. I've talked to all of you. And I believe you all share a common ground... and I think Jay hit it square on the nose. You guys all want what's best for your Mother.

DR. BARLOW

Judging by the nods I just saw to Wesley's comment it's safe to say that what he's said is true. So maybe we can start from this common ground. Mrs. Allen I know you're tired but after hearing your children would you be willing to consider a few options?

MRS. ALLEN What would be the options?

DR. BARLOW

Well, that would depend on what your goals are. We could start there and work out what best suits you... but first you might want to consider what Sandra said. Maybe you are depressed. You've been

through a lot. If you like we could have a psychiatrist come in and have a talk with you. That way your children will know that we've done everything possible to help you.

MRS. ALLEN I'm not depressed.

CATHY How do you know that? Would it hurt to just talk to someone?

MRS. ALLEN I can't argue with that. But I don't know. It's just so much right now...

DR. BARLOW

Mrs. Allen, you don't have to decide right now... think about it. If you would like we can arrange another meeting for later on in the week to discuss this further.

MRS. ALLEN

Okay... alright... I'll think about it. I'll need some time though. Can we make an appointment for later this week?

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario screen up
Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

This scenario illustrates how family meetings can provide effective opportunities to share information, concerns and gain insight into a patient and family's understanding of the situation.

Healthcare providers gain insight into family function by seeing how families interact with each other at a family meeting.

These insights can help inform strategies for better care and support to the patient and family as a whole.

It's essential to facilitate a safe, managed environment in a meeting and allow everyone to express their views, concerns, hopes and fears.

There is an important role for listening to family, but it must be balanced with education and leadership by the care team.

Poorly managed meetings can escalate conflict and worsen relations within the family and between the family and the care team.

Healthcare providers have an opportunity to explore patient's and family member's hopes, fears, needs and desires, and clarify and educate in the midst of conflict.

END OF SEGMENT

SEGMENT (PDV007)
DISCUSSING GOALS OF CARE (ENGAGING TRANSITIONS)

Running Time (without participant discussion) – 5 min, 56 sec

Access at

<http://archive.org/details/DiscussingGoalsOfCareengagingTransitionspdv007>

Suggested Uses

- Exploring opportunities that exist to help patients discuss transitions
- Discussing issues for leadership and support at those times in the provision of care when there is an identifiable transition point from curative or disease modifying therapy to palliative care service
- Recognizing the importance of patient feelings of abandonment when curative treatment is no longer viable and facilitating a 'reverse referral' back to a primary-care physician/team when a specialist disengages treatment
- Discussing issues in managing boundaries in relationships with providers and patients, including what is reasonable and realistic to commit to and how the specific context of a patients' circumstances operate as mitigating factors

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents two ill-structured clinical scenarios. It's not intended to model but rather to promote critical reflection and group discussion on the challenges of advanced planning dialogue.

The segment is about a home care nurse named Carrie visiting her patient Julia. Julia has just been told that there is no more curative chemotherapy options to control her advanced cancer.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO ONE

PATIENT (Julia) I saw Dr. Croft, my oncologist, yesterday.

HOME CARE NURSE (Carrie) And what did he say?

PATIENT (Julia) Wasn't good news...

HOME CARE NURSE (Carrie) Not good news?

PATIENT (Julia)

No... he says that we've pretty much run out of options. He's not able to give me any more chemo. The liver metastasis is still growing even with the chemo treatments. He suggested that I should see my family Physician from now on.

HOME CARE NURSE (Carrie)

You're family doctor is a great physician Julia! He'll look after you.

PATIENT (Julia)

I got the impression from Croft that there isn't anything anyone can do to help me anymore.

HOME CARE NURSE (Carrie)

Don't think like that... that's so negative. You know we'll look after you no matter what.

PATIENT (Julia) Yeah, right. Positive thinking hey! You're a big help.

HOME CARE NURSE (Carrie) So, when are you going to see him?

HOME CARE NURSE (Carrie) Tomorrow.

HOME CARE NURSE (Carrie)

I'm sure when you talk to him tomorrow he'll be able to suggest something to help you...how's your pain?

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario One screen up

Pause for Discussion

Press **PAUSE** key and debrief

SECOND SCENARIO

Press **PLAY** key / **PAUSE** key

SOCIODRAMA SCENARIO TWO

PATIENT (Julia) I saw Dr. Croft, my oncologist, yesterday.

HOME CARE NURSE (Carrie) And what did he say?

PATIENT (Julia) Wasn't good news...

HOME CARE NURSE (Carrie) Not good news?

PATIENT (Julia)

No... he says that we've pretty much run out of options. He's can't give me anymore chemo. The metastases is growing in spite of the chemo... He suggested that I should see my family doctor from now on.

HOME CARE NURSE This must be a very difficult time for you. How does that make you feel?

PATIENT (Julia)

Hopeless... abandoned... I don't think there are enough words to describe the way I'm feeling.... Dr. Croft has been my doctor for so long... I trusted him... I counted on him. Now he's gone... and I don't know where to go from here.

HOME CARE NURSE (Carrie) You know the cancer cells in your liver can't be cured but there are a lot of things your family doctor and I can do to help keep you comfortable and live as normal life as possible.

PATIENT (Julia) What can you do to help me?

HOME CARE NURSE (Carrie)

Well, first of all, I could give your family doctor, Dr. Scott... right.

I'll give Dr. Scott a call right away and I'll set up an appointment for you to see him. And, you and I can discuss with him we'd like to go from here.

PATIENT (Julia) Would you come with me? I don't know what to ask him.

HOME CARE NURSE (Carrie)

Well, we'll see when we can get an appointment and if I'm not booked then...yes, of course I'll come with you.

But... in the meanwhile, you and I can talk about what we'd like to ask him...make a list.

PATIENT (Julia) That would help.

HOME CARE NURSE (Carrie) I'll be with you every step of the way.

PATIENT (Julia) Thanks.

HOME CARE NURSE (Carrie)

And when I'm done making this appointment we should talk about the pain you've been having in your arm, now I've noticed the...

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario Two screen up
Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

The transition from curative therapy to a focus on palliative therapy can be traumatic for patients and family. It's a time of profound transition.

It's also common to encounter fear of abandonment as patients and families come to realize their situation has become life-limiting.

Refocusing and maintaining hope is a key way that providers can help patients cope with the changes they are facing.

Through being present in the moment and careful listening, the provider can explore the deeper meaning of what the patient is saying.

You have the ability to help uncover fears and concerns about the future and feelings of hopelessness.

You also have the ability to support the patient by refocusing hope on realistic goals.

END OF SEGMENT

SEGMENT (PDV008)
DISCUSSING GOALS OF CARE (HASTEN DEATH REQUEST)

Running Time (without participant discussion) – 7 min, 14 sec

Access at

<http://archive.org/details/DiscussingGoalsOfCarehastenDeathRequestpdv008>

Suggested Uses

- Discussing common issues operating in patient-family/provider dynamics that might present and manifest in a request to hasten death
- Discussing the importance of recognizing the prospect of Existential Suffering or Total Pain/Suffering as part of continual assessment and diagnosis
- Exploring the potential for well-intended family dynamics/expectations to contribute in complicating life closure and contributing to existential suffering

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents two ill-structured scenarios. It's not intended to model but rather to promote critical reflection and group discussion.

The scenario presents an elderly woman named Doris who has advanced ALS. Due to muscle weakness associated with the bulbar nerves she can no longer speak or swallow.

She is concerned about how she might die and is worried about the growing burden she believes is being placed on her family. She presents her physician with a note requesting help to hasten her death.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO ONE

DORIS (Monologue to audience)

I used to love the mornings, but since I've gotten so sick... I hate mornings, they're always followed by very long days. Days of choking, followed by sleepless nights.... I can't remember when I've had a decent night's sleep. I'm so sick of not being able to talk anymore... using sign language and writing notes. It's just all so hard. I'm a burden for my daughters... I'm a burden for my whole family... I'm sure that they all be glad to see me go. They must be getting tired of coming here and looking after me.

I'm giving this note to my Physician... TODAY... I want it all to end. I don't want to live a moment longer like this. She must have some medications that she can give me to make it fast and painless. I'm sure she'll understand...

PHYSICIAN Doris, you mean this?

PHYSICIAN

You know I can't do this... I understand how hard this must be on you. This illness it takes its toll on one physically as well as emotionally.

GRAND DAUGHTER (CATHERINE) What did she say in the note?

PHYSICIAN

Don't worry Doris we're all here for you. We're all here, to make you as comfortable as we can. Now let's see how you're doing today.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario One screen up
Pause for Discussion

Press **PAUSE** key and debrief

SECOND SCENARIO

Press **PLAY** key / **PAUSE** key

SOCIODRAMA SCENARIO TWO

PHYSICIAN (reading the patient's note) Doris, you mean this?

PHYSICIAN This illness takes its toll not only physically but emotionally.

GRAND DAUGHTER (CATHERINE)What did she say?

PHYSICIAN I think she'd like you to see this as well. It's addressed to me as well as the family.

GRAND DAUGHTER (CATHERINE – reading the patient's note) I'm a burden to everyone, my daughters and my grandchildren. I've outlived my time. I want this to be over. Can you speed this up?

PHYSICIAN By speeding things up, you're asking me to end your life?

PHYSICIAN Any pain?

PHYSICIAN Some pain... where?

PHYSICIAN We can give you something for the pain and it will make you feel more comfortable.

GRAND DAUGHTER (CATHERINE)

Grandma, you're not a burden to the family... I love coming to visit you and look after you.

GRAND DAUGHTER (CATHERINE)Please don't give up Gram. I know this must be hard for you, but we all love you so much... And besides you promised to be there for me when I graduated from college.

PHYSICIAN

This is a difficult time for you... but I know your Granddaughter enjoys your visits. And, both your daughters know how important it is to have the opportunity to still spend time with you.

GRAND DAUGHTER (CATHERINE) Listen to Doc Hildee, Gramma... what she says is true. You're not a burden. And it might be selfish of us, but we don't want you to go. We love you so much.

PHYSICIAN

I understand that choking is tiring but we can help you with that... I'll write a new prescription and orders for the home care nurse... we can make you more comfortable.

And the breathing too...I can give you medication that will help with your shortness of breath. We can start right today and see how you do with it. Just tell us when you need help and when you're uncomfortable.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario Two screen up
Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

As the segment illustrates, some people worry about how they will die and if they are being a burden on their family. They may explore what can be done, or simply request something to accelerate resolution of the situation.

As a result care providers can be faced with difficult moral, ethical and legal questions.

In a situation where a patient is not cognitively impaired, but is also not easily able to verbally express their concerns, it's helpful to find other means of communicating so issues and fears can be properly explored.

Listening to the deeper meaning of a request and discussing the suffering can help address the underlying issues in a way that can be addressed.

It can be helpful to appropriately share these concerns with a family so that they might address the issues that only a family can answer.

END OF SEGMENT

SEGMENT (PDV009)
DISCUSSING AND DEMYSTIFYING THE LAST HOURS
Running Time (without participant discussion) – 5 min, 49 sec

Access at

<http://archive.org/details/DiscussingGoalsOfCarehastenDeathRequestpdv008>

Suggested Uses

- Exploring the importance of communicating to family members common physiological changes with which many patients will likely present during the last hours of life
- Discussing predictable dynamics associated with suffering which family members might present with during end-stage (i.e., last hours) vigils with a dying family member

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

The following dramatization presents two ill-structured scenarios. It's not intended to model but rather to promote critical reflection and group discussion about the things family members might experience close to end-of-life, especially when not well informed and supported.

In the following scene, a patient is in the last hours of life and dying from cancer. She is attended by her husband who wishes to be with her until the end. He is concerned and distressed and expresses his concerns to the care team.

As you watch the segment, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO ONE

NURSE So, how are you doing?

ALEX I'm okay. When she breathes like that... is... is she in pain?

NURSE No. This breathing is just part of the process.

ALEX

Isn't there something more we can do for her? I mean, it's really hard watching her like this - and you know - worrying that she might be suffering.

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario One screen up
Pause for Discussion

Press **PAUSE** key and debrief

SECOND SCENARIO

Press **PLAY** key / **PAUSE** key

SOCIODRAMA SCENARIO TWO

ALEX

It's just not right. I mean, we treat our animals better than this... we don't let them linger and suffer like Julia's suffering. We call it being humane.

PHYSICIAN In what way do you feel Julia is suffering?

ALEX

You just have to look at her. She's yellow... for heaven's sake. She's breathing funny, making wheezing sounds... she's suffering.

PHYSICIAN

Alex, I understand that you think Julia is suffering. But the color of her skin is a result of her liver failing and it doesn't cause her any pain. That wheezing you hear is the result of her unconscious state and the way the air is flowing over her vocal cords. The weird breathing is a sign that her body's respiratory control is being affected by the toxins in the liver.

ALEX Right... and just how do you know that?

PHYSICIAN

It's part of the natural process of dying. It's the body's way of gradually shutting down systems. It's difficult for us to know if someone is actually suffering because no one has ever been able to tell us what they are experiencing. So we have to go by facial expressions and movements.

ALEX That's it? That doesn't sound very scientific to me.

PHYSICIAN

Well that may be so, but we feel that if someone is sleeping peacefully, then they are comfortable. I think that the process of dying is much like the process of being born. There is a labor beforehand and there's no way of knowing how long that will take.

ALEX Maybe that's so, but it's hard to just sit there and watch her slipping away like that.

PHYSICIAN I'm sure that it must be Alex. You have a little girl, don't you?

ALEX Yeah, why?

PHYSICIAN Where is she when you're here?

ALEX Well, she's with my wife's sister sometimes and other times she's with my mother...

PHYSICIAN Sounds like you have a supportive family.

ALEX They've been great.

PHYSICIAN

Why don't you ask them to share this vigil with you, and you go home and spend some time with your daughter...she needs you too.

ALEX

I suppose, but I'm afraid that Julia will pass away when I'm not there with her. I don't want her to go away, when I'm not there. I feel so guilty... there's nothing I can do... but I have to be there for her. Even if all I can do is sit by her side and wait.

PHYSICIAN

Alex, there are some things you can do for her. Like keeping her lips and mouth moist, massaging her arms and legs, playing some music she likes and some other things too. Let's go and see her, I'll show you...

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario Two screen up
Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

This segment highlights that helping families to know about the natural process of dying can help reduce fear about what is happening and address concerns about the extent of suffering experienced by their loved one.

The last hours of life often follow an extended period of illness and decline. It's likely and understandable that family members may be very distressed and exhausted.

Involving family in the care of their loved one is central to helping family members through the transition from life to death.

END OF SEGMENT

SEGMENT (PDV010)
PRACTICAL COLLABORATIVE TEAM WORK IN ADVANCED ILLNESS

Running Time (without participant discussion) – 4 min, 43 sec

Access at

<http://archive.org/details/PracticalCollaborativeTeamWorkInAdvancedIllness>

Suggested Uses

- Discussing the value of inter-professional case conferencing as a way of joint problem-solving for complex patient care issues
- Exploring the possibility of a broad definition of team in primary-care settings to achieve goals of care
- Discussing how failure to achieve advanced care planning as a family unit can manifest and complicate patient care during the decline process

SETUP NARRATIVE AT FRONT OF SEGMENT

Press **PLAY** key to start segment

In the following scenario, a First Nations elder named Mr. Thomas Joe is near end-of-life and decisions are required. An inter-professional case conference has been called to address end-of-life decisions before Mr. Joe loses capacity to participate in decision making:

As you watch, consider the following questions:

- What is happening?
- What issues does it raise?
- What emotions come to your awareness?
- What implications does it have for how we practice?

SOCIODRAMA SCENARIO

PHYSICIAN (Monologue to audience)

At a patient conference today I am presenting Mr. Joe's case. He is a patient nearing the end of his life. We anticipate that he won't be conscious for much longer and there are some decisions that have to be made about how we deal with his passing. Do we resuscitate him? Where would he like to spend his last days? Things like that. Our problem is that he is not communicating with us and his daughter is the only one who visits him and she won't talk to me or the nurses. His brother and sister are in denial and don't visit and his wife has already passed away. We need to know what to do for him and I am not sure what our options are in this case.

ABORIGINAL CULTURAL HELPER

So, has anyone tried to communicate with Mr. Joe about what he wants?

NURSE

He has talked to me a couple of times. By all indications he wants the family to make decisions for him when the time comes.

SOCIAL WORKER

I have known the family for some time now and they are uncomfortable discussing anything about Thomas. I don't think they are ready to let him go.

PHYSICIAN They haven't talked to me either... and really neither has Mr. Joe.

ABORIGINAL CULTURAL HELPER

I've found many patients are more comfortable talking to their nurses.

NURSE

The family is very quiet and self-contained. And the brother and sister are still in denial.

ABORIGINAL CULTURAL HELPER

You know, there is George who is an Aboriginal man on staff with me. He is from the same community as Mr. Joe.

SOCIAL WORKER You know, we really have to act quickly. How do we proceed?

ABORIGINAL CULTURAL HELPER

I can visit with Mr. Joe and see if he would like to talk with George. I believe they have similar values. Mr. Joe, his family and George could have a chat together.

NURSE

His daughter has spoken with me a few times. Maybe I can have a word with her in private. I'll try and set that up the next time that she comes in.

SOCIAL WORKER That's a good idea!

PARTICIPANT DISCUSSION & DEBRIEF

End of Scenario One screen up
Pause for Discussion

Press **PAUSE** key and debrief

TEACHING POINTS/SUMMATION

Press **PLAY** key / **PAUSE** key

Providing hospice palliative care is complex and requires a range of skills, perspectives and leadership from a diversity of providers.

It demands interdependence among providers and a willingness to share strengths and accountability for problem-solving and managing care.

Team does not always mean individuals whose responsibility is joint contribution to a particular unit or care task, but rather who is the most appropriate to help achieve the goals of care in a given situation. This is particularly so in tightly resourced primary-care settings.

Being open-minded, creative and engaged about who is the most appropriate person to help a patient and family in planning care is an important example of working collaboratively as a team.

Being open to the perspectives of colleagues from various disciplines can be a productive way of exploring complex care planning and jointly approaching seemingly intractable problems.

It can reveal issues, concerns and options that are not apparent to any one care provider involved with a patient and family.

END OF SEGMENT

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APPENDIX – SEGMENT/LESSON PLANNING WORKSHEET
(Photocopy this sheet as you need it)

SEGMENT TITLE _____

The learning objectives I am addressing in use of a segment are:

The teaching points I want to ensure are covered in use of a segment include:

Post segment-use completion Insights/joint-learning from participant discussion in use of this segment that I would like to ensure are covered in future teaching points are: